

# BMJ Open Strategies for engaging senior citizens and their informal caregivers in health policy development: a scoping review protocol

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## ABSTRACT

**Introduction** Care for senior citizens is a global policy issue. There has been limited focus on senior citizen and informal caregiver engagement in policy development. Encouraging senior citizen participation through active engagement in the policymaking process enhances the provision of better services and the creation of responsive policies and is critical to better healthcare. Accordingly, this review aims to map the available evidence to provide an overview of strategies for engaging senior citizens and informal caregivers in health policy development.

**Methods and analysis** A scoping review will be conducted. This study will use the updated methodological guidance for conducting a scoping review developed by the Joanna Briggs Institute. This review aims to answer the question: 'What is known in the literature about strategies for engaging senior citizens and informal caregivers in health policy development?' Titles and abstracts will be screened to determine eligibility for full-text review based on already established eligibility criteria. Data will be extracted from relevant articles. A summary of extracted data will be presented. The results will be interpreted within the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.

**Ethics and dissemination** Ethical review is not required as scoping reviews are a form of secondary data analysis that synthesises data from publicly available sources. Findings from this proposed review will be disseminated in conferences and to the global scientific community through published academic papers in reputable health policy-related journals.

## INTRODUCTION

Around 16% of the world's population is predicted to be 65 years or older in 2050.<sup>1</sup> Care needs increase with age, and senior citizens have unmet care needs related to their physical and psychological health, social life, and the environment in which they live and interact.<sup>2</sup> Senior citizens are extensive users of health and social care services and are greatly affected by health policy decisions across all care settings. Similarly, informal caregivers assume many different roles in providing care support for senior citizens, thus constituting a heavy burden on them.<sup>3</sup> Their input or that

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first known review that seeks to address knowledge and evidence gaps on strategies for engaging senior citizens and informal caregivers in health policy development from existing literature.
- ⇒ The review will build on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare, thus a theoretical contribution to the literature.
- ⇒ Publications will be searched from multiple electronic databases with peer-reviewed literature and a broad range of grey literature sources, using a comprehensive search strategy, thus an opportunity to retrieve all potentially relevant publications.
- ⇒ All languages will be included, thereby reducing publication bias based on the language of publication.
- ⇒ According to scoping review methods, the optional quality assessment of articles will not be performed.

of their informal caregivers in health policy development is under-represented.<sup>4</sup> Little is known about strategies used to engage them in designing or implementing policies that matter to them.<sup>5</sup> Yet senior citizens and their informal caregivers should have a voice in decisions associated with them since involving their perspectives in all stages of policymaking can improve the success and ownership of policies and sustainability of the outputs.<sup>6</sup> As most previous research on engagement at the policy level focuses on the general population, this does not often reflect senior citizens' unique and complex social and healthcare needs.

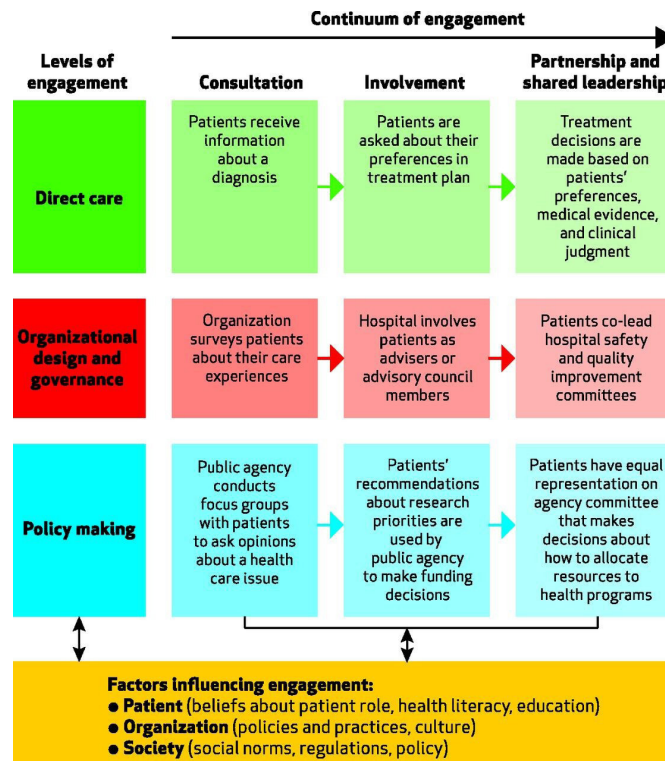
Citizen engagement and deliberative methods can change knowledge and attitudes,<sup>7</sup> promote active citizenship, and improve relationships between the government and citizens.<sup>8,9</sup> Effective citizen engagement and public deliberation can also lead to improved outcomes for citizens, policymakers and policymaking. When citizens are engaged, policymakers are better aware of what outcomes need to be addressed. Citizen

engagement can improve multiple types of outcomes such as instrumental, developmental and democratic outcomes. *Instrumental outcomes* mean generating awareness of lived experience and improving the quality of policymaking by ensuring that policies, programmes, and services align with the values and needs of citizens, provision of better services, healthcare and improved quality of care,<sup>10,11</sup> and the creation of responsive policies.<sup>12–14</sup> *Developmental outcomes* mean providing education and raising awareness about pressing health issues and developing citizens' capacity to take part in public policy matters,<sup>15</sup> and *democratic outcomes* mean supporting transparency, accountability, trust and empowerment.<sup>9, 16–18</sup> Citizen engagement benefits individuals, organisations, and society by increasing knowledge, power, and problem-solving ability.<sup>19</sup> Finally, involving citizens in policy decisions can increase the legitimacy and transparency of decision-making processes and help inform health policy decisions.<sup>20</sup> Senior citizen and informal caregiver engagement in policy is pivotal as health policy decisions are not only relevant to them but also impact the healthcare system.

Previous research has tried to understand mechanisms needed to engage senior citizens in healthcare decision-making, research and planning.<sup>21, 22</sup> However, there is limited published literature specifically focused on senior citizen and informal caregiver engagement in health policy development. Most existing research focuses on *all citizens'* engagement in research and at point of care. Similarly, there is a dearth of literature on caregiver engagement in health policy development. Few examples for caregiver engagement in health policy development exist. For example, Keogh *et al*<sup>23</sup> described the use of an innovative approach, being Carers assembly to increase the involvement of caregivers of people with dementia in the policymaking process in Ireland.

Thus, this current scoping review aims to provide an overview of available research evidence on strategies for senior citizens' and informal caregivers' engagement in health policy decision-making. This research synthesis aims to map the literature on strategies for senior citizens and informal caregiver engagement in health policy and to provide an opportunity to understand key concepts and identify knowledge gaps on engagement strategies. The review will provide an evidence-based foundation to guide senior citizen engagement in health policy development and demonstrate how engagement strategies have been used in health policy development in different contexts.

This scoping review will be the first to synthesise the existing evidence on strategies for senior citizen and informal caregiver engagement in health policy development as described in peer-reviewed and grey literature. It is thus a novel scoping review to identify and describe engagement strategies for senior citizens and informal caregivers as used in different contexts.



**Figure 1** A Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.<sup>28</sup>

## METHODS

### Scoping review design

This scoping review will follow the approach recommended by the Joanna Briggs Institute.<sup>24</sup> The scoping review methodology was chosen for its suitability for addressing our proposed topic as it will provide an opportunity to assess the extent of the available evidence on engagement strategies for senior citizens and informal caregivers in health policy development, as well as identify and analyse knowledge gaps.

Senior citizens will refer to persons aged 65 years and above for this review. The term *citizen* will be used more comprehensively without discrimination to refer to every person in a society or country.<sup>25</sup> *Informal caregiver* is an unpaid individual (for example, a spouse, partner, family member, friend or neighbour) involved in assisting others with activities of daily living and medical tasks.<sup>26</sup> *Citizen engagement* is defined as the meaningful involvement of individual citizens in policy or programme development, from agenda setting and planning to decision-making, implementation and review.<sup>27</sup>

### Conceptual model

This scoping review will use the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare proposed by Carman *et al*<sup>28</sup> (figure 1), which was influenced by Arnstein's "ladder of citizen participation."<sup>29</sup> This framework presents engagement in three elements: continuum, levels and factors influencing engagement. These three elements will guide in mapping evidence from the literature. It outlines a continuum of

**Table 1** Search strategy

Database	Concept	Search terms
PubMed	Senior citizen	("Aged"[Mesh] OR "aged patient"[tiab] OR "aged people"[tiab] OR "aged person"[tiab] OR "aged adult"[tiab] OR "aged citizen"[tiab] OR elder[tiab] OR "oldest old"[tiab] OR "older adult"[tiab] OR "older patient"[tiab] OR "older subject"[tiab] OR "older citizen"[tiab] OR "older person"[tiab] OR "older people"[tiab] OR senior[tiab] OR "old age"[tiab] OR "advanced age"[tiab] OR aging[tiab] OR ageing[tiab] OR "Geriatrics"[Mesh] OR geriatr[tiab] OR gerontolog[tiab] OR Centenarian[tiab] OR Nonagenarian[tiab] OR Octogenarian[tiab] OR septuagenarian[tiab])
	Engagement	"Patient Participation"[Mesh] OR participat[tiab] OR Empower[tiab] OR Activat[tiab] OR Deliberat[tiab] OR engag[tiab] OR involv[tiab] OR "Stakeholder Participation"[Mesh] OR "stakeholder role"[tiab]
	Health policy and development	"Health Policy"[Mesh] OR "health polic"[tiab] OR "healthcare polic"[tiab] OR "health care polic"[tiab] OR "Policy Making"[Mesh] OR "policy making"[tiab] OR "policymaking"[tiab] OR "policy development"[tiab] OR "policy analys"[tiab] OR "advisory committ"[tiab] OR "task force"[tiab] OR "review committ"[tiab] OR "policy formulation"[tiab] OR "policy evaluation"[tiab] OR "health care reform"[tiab] OR "healthcare reform"[tiab]
Embase	Senior citizen	'aged'/exp OR 'the aged':ti,ab,kw OR 'aged patient':ti,ab,kw OR 'aged people':ti,ab,kw OR 'aged person':ti,ab,kw OR 'aged adult':ti,ab,kw OR 'aged citizen':ti,ab,kw OR 'elder':ti,ab,kw OR 'oldest old':ti,ab,kw OR 'older adult':ti,ab,kw OR 'older patient':ti,ab,kw OR 'older subject':ti,ab,kw OR 'older citizen':ti,ab,kw OR 'older person':ti,ab,kw OR 'older people':ti,ab,kw OR 'senior':ti,ab,kw OR 'old age':ti,ab,kw OR 'advanced age':ti,ab,kw OR 'aging':ti,ab,kw OR 'ageing':ti,ab,kw OR 'geriatrics'/exp OR 'geriatr':ti,ab,kw OR 'gerontology'/exp OR 'gerontolog':ti,ab,kw OR 'Centenarian':ti,ab,kw OR 'Nonagenarian':ti,ab,kw OR 'Octogenarian':ti,ab,kw OR septuagenarian':ti,ab,kw
	Engagement	'patient participation'/exp OR 'patient engagement'/exp OR 'patient empowerment'/exp OR 'stakeholder engagement'/exp OR 'patient activation'/exp OR 'participat':ti,ab,kw OR 'Empower':ti,ab,kw OR 'Activat':ti,ab,kw OR 'engag':ti,ab,kw OR 'involv':ti,ab,kw OR 'deliberation'/exp OR 'deliberat':ti,ab,kw OR 'stakeholder role':ti,ab,kw
	Health policy and development	'health care policy'/exp OR 'health care polic':ti,ab,kw OR 'health polic':ti,ab,kw OR 'healthcare polic':ti,ab,kw OR 'policy making':ti,ab,kw OR 'policymaking':ti,ab,kw OR 'policy development'/exp OR 'policy development':ti,ab,kw OR 'policy analys':ti,ab,kw OR 'advisory committ':ti,ab,kw OR 'task force':ti,ab,kw OR 'development of polic':ti,ab,kw OR 'review committ':ti,ab,kw OR 'policy formulation':ti,ab,kw OR 'policy evaluation':ti,ab,kw OR 'health care reform':ti,ab,kw OR 'healthcare reform':ti,ab,kw
CINAHL	Senior citizen	(MH "Aged") OR (MH "Geriatrics") OR (MH "Caregivers") OR TI (Elder* OR "Older Persons" OR the aged OR "aged patient" OR "aged people" OR "aged person" OR "aged adult" OR "aged citizen" OR "oldest old" OR "older adult" OR "older patient" OR "older subject" OR "older citizen" OR "older person" OR "older people" OR "senior" OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) OR AB (Elder* OR "Older Persons" OR "the aged" OR "aged patient" OR "aged people" OR "aged person" OR "aged adult" OR "aged citizen" OR "oldest old" OR "older adult" OR "older patient" OR "older subject" OR "older citizen" OR "older person" OR "older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR geriatr* OR gerontology OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*)
	Engagement	(MH "Consumer Participation") OR (MH "Political Participation") OR (MH "Stakeholder participation") OR TI (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role") OR AB (participat* OR Empower* OR Activat* OR Deliberat* OR Engag* OR involv* OR "stakeholder role")
	Health policy and development	(MH "Policy Making") OR (MH "Health Policy+") OR TI ("Health polic" OR "healthcare polic" OR "health care polic" OR policymaking OR "policy making" OR "policy development" OR "policy analys" OR "advisory committ" OR "task force" OR "development of polic" OR "review committ" OR "policy formulation" OR "policy evaluation" OR health care reform* OR healthcare reform*) OR AB ("Health polic" OR "healthcare polic" OR "health care polic" OR policymaking OR policy making" OR "policy development" OR "policy analys" OR "advisory committ" OR "task force" OR "development of polic" OR "review committ" OR "policy formulation" OR "policy evaluation" OR health care reform* OR healthcare reform*)
Health systems evidence	Older adult* OR caregiver* AND participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* AND "Health Policy" OR "health polic" OR "healthcare polic" OR "health care polic" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development" OR "policy analys" OR "advisory committ" OR "task force" OR "development of polic" OR "review committ" OR "policy formulation" OR "policy evaluation" OR health care reform* OR healthcare reform*	
Health evidence	Senior citizen ("Aged" OR "the aged" OR "aged patient" OR "aged people" OR "aged person" OR "aged adult" OR "aged citizen" OR elder* OR "oldest old" OR "older adult" OR "older patient" OR "older subject" OR "older citizen" OR "older person" OR "older people" OR senior* OR "old age" OR "advanced age" OR aging OR ageing OR "Geriatrics" OR geriatr* OR gerontolog* OR Centenarian* OR Nonagenarian* OR Octogenarian* OR septuagenarian*) AND ("Patient Participation" OR participat* OR Empower* OR Activat* OR Deliberat* OR engag* OR involv* OR "stakeholder role") AND ("Health Policy" OR "health polic" OR "healthcare polic" OR "health care polic" OR "Policy Making" OR "policy making" OR "policymaking" OR "policy development" OR "policy analys" OR "advisory committ" OR "task force" OR "development of polic" OR "review committ" OR "policy formulation" OR "policy evaluation" OR health care reform* OR healthcare reform*)	

engagement activities (consultation, partnership and shared decision-making) across three levels of the healthcare system (individual care, organisational governance and government policy) and describes factors influencing engagement. The framework presents engagement at the personal level of care as considering patients' preferences and values in treatment decisions. At the organisational care and governance level, patients' and families' perspectives are considered in the design and governance

of healthcare organisations and projects. Engagement at the policymaking level is centred on developing, implementing, and evaluating healthcare programmes and policies through collaborations between citizens and policymakers.<sup>28</sup> Engagement occurs at the lower end of the continuum but with a limited effect on decision-making. In contrast, there is active partnership, signified by a bidirectional flow of information at the higher end and shared decision-making responsibility. Furthermore, this

## Box 1

**Scoping Review Details**

Article title

Review objectives

Review questions

Study type (case, empirical, review)

Study design (quantitative, qualitative)

**Evidence source details and characteristics**

Citation details

Country/geographical setting

Context participants/population studied (age, sex, number)

**Inclusion/Exclusion Criteria****Population**

Includes senior citizens aged 65 and above and/or their informal caregivers

**Concept**

Describes strategies for senior citizen and informal caregiver engagement

**Context**

Describes strategies for senior citizen and informal caregiver engagement in policies around health and well-being

**Details/results extracted from publications**

Name of engagement strategies discussed

Description of strategy

Stated continuum of engagement (consultation, involvement, partnership, and shared leadership)

Stated phase of policy development (e.g. policy formulation, implementation, or evaluation)

Stated factors influencing policy makers to create opportunities for engagement in health policy development

Stated outcome(s) of engagement strategies:

Change in knowledge and attitude of engaged senior citizens and informal caregivers

Promotion of active citizenship (e.g., do senior citizens and informal caregivers feel a sense of citizenship and participation in decision making)

Impact on relationship between the government and the citizens

Senior citizens' and informal caregivers' awareness of one-another's lived experiences

Increased knowledge about care transitions and engagement

Developed capacity to take part in public policy matter

Any other reported outcomes

Data on comparisons of different engagement approaches

Data on efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated

How strategy was used for engagement in health policy development

Health policy topics discussed using engagement approaches

Stated engagement frameworks discussed

study will expand on the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare<sup>28</sup> by including components in the extraction table specific to senior citizen and informal caregiver engagement in health policy development. The scoping review will identify and describe different strategies/methods for senior citizen and informal caregiver engagement in health policymaking. More specifically, this review will extract and synthesise data on items relevant to the framework: continuum of engagement, phase of policy development in which engagement occurs, factors influencing

engagement and engagement outcomes. Additionally, outcomes of engagement, comparisons of engagement strategies, and efforts to involve minority groups will also be extracted and synthesised.

**Search strategy**

In line with the Joanna Briggs Institute recommendations,<sup>24</sup> a three-step search strategy will be used. An initial limited search of two online databases (MEDLINE (through PubMed) and Embase) will be conducted. This search will use the search strategy in [table 1](#). This will be followed by an analysis of the keywords in the title and abstract of retrieved papers and the index terms used to describe the articles. A second search will use all identified keywords and index terms across other databases: Health Systems Evidence, Health Evidence and CINAHL. Third, the reference lists of identified reports and articles will be searched for additional sources. We will work with a librarian for the refinement of the search strategy and conducting the search on all relevant databases. Authors of primary sources or reviews will also be contacted when necessary for further information. With consultation from stakeholder groups and major international organisations, sources that would hold grey literature on practices for engaging senior citizens and their informal caregivers in health policy development will be identified. A search will be conducted, and all available information will be retrieved.

Search results will be imported into EndNote V.20 where duplicates will be removed, then into an online systematic review software, Covidence ([www.covidence.org](http://www.covidence.org)). Titles and abstracts will be screened to determine eligibility for full-text review based on the eligibility criteria described in the following section. All research team members will first screen a sample together using the eligibility criteria, then two researchers will independently screen all titles and abstracts. Disagreements will be discussed and resolved through discussion or involving a third team member, and consensus will be reached. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of the literature search and selection process will be presented. The study is being conducted between April and November 2022.

**Inclusion/exclusion criteria**

Empirical studies, for example, qualitative, quantitative, and mixed-methods research, systematic and scoping reviews, and grey literature reports will be included if they report on policy development in the areas of health and well-being; address the use or evaluation of a method/practice for engaging senior citizens and informal caregivers in health policy development; focus on senior citizens defined as persons with a minimum age of 65 years (or a majority of participants are aged 65 years and above), and/or their informal caregivers or addressed with proxy words such as chronically ill, dementia, and frail elderly; and address policy development at regional, national, or international level.

Due to a dearth of literature on senior citizen engagement in health policy development, there will be no limit to publication year. There will be no language restrictions included in the eligibility criteria and in the search strategy. This means that search results in every language (of the world/where an article on the subject has been written) generated from our search strategy will be included for review, if they meet all other eligibility criteria. Abstracts of studies in languages other than English will first be translated using the help of a colleague who is proficient in the language. If considered relevant, the full texts will then be translated using the help of a translation firm. Studies discussing senior citizen and informal caregiver engagement in research or at the point of care will be excluded. Studies addressing *all* citizen engagement with no particular attention to senior citizens will be excluded.

### Data charting, summarising and reporting the results

A preliminary data charting table (see [box 1](#)) has been developed and will be piloted to familiarise with results, based on the elements presented in the engagement framework by Carman *et al.*<sup>28</sup> This Multidimensional Framework for Patient and Family Engagement in Health and Healthcare will be used to guide analysis and data will be categorised based on its elements. We will first capture information on engagement approaches used in the included relevant articles, their characteristics and how they were used to engage senior citizens and/or informal caregivers in health policy development. Then, we will interpret these findings based on the elements in the framework. We will extract data on continuum of engagement, phase of policy development, factors influencing policymakers to create opportunities for engagement, outcomes of engagement, comparisons of engagement strategies, and efforts/initiatives to ensure engagement of senior citizens of minority groups, if stated. Two researchers will pilot the data extraction table. The table will be further refined and updated as required in accordance with the review's objectives. A descriptive summary of the findings will be presented. Data on authors, sources of evidence, year of publication, country/origin/setting of study, and engagement frameworks will be extracted and presented. Regardless of the study designs of the included studies, the descriptions of the engagement strategies reported in the included studies will be the focus of the analysis, and this will be guided by the Multidimensional Framework for Patient and Family Engagement in Health and Healthcare.

### Patient and public involvement

There was no patient nor public involvement.

### Ethics and dissemination

This study does not require ethical approval as it will use publicly available data and does not involve human subjects' research. This study will constitute the first step in a research plan aimed at identifying engagement strategies and comparing them for variation, content, and

breadth and depth of insights. The findings of this review will guide researchers, stakeholders, government and non-governmental organisations as well as policymakers in conversations around engagement in this context.

### Data sharing statement

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not required.

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### REFERENCES

- 1 UNDESA. *World population ageing 2020 highlights*. division DoEaSAP, 2020.
- 2 Abdi S, Spann A, Borilovic J, *et al.* Correction to: understanding the care and support needs of older people: a scoping review and categorisation using the who International classification of functioning, disability and health framework (ICF). *BMC Geriatr* 2020;20:23.
- 3 Gauvin F-P, Ganann R, Heald-Taylor G. Engaging older adults with complex health and social needs, and their caregivers, to improve Hospital-to-home transitions in Ontario, 2019
- 4 Holroyd-Leduc J, Resin J, Ashley L, *et al.* Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy. *Res Involv Engagem* 2016;2:23.
- 5 Falanga R, Cebulla A, Principi A, *et al.* The participation of senior citizens in policy-making: patterning initiatives in Europe. *Int J Environ Res Public Health* 2020;18. doi:10.3390/ijerph18010034. [Epub ahead of print: 23 12 2020].
- 6 Stefanoni S, Camilla W. *Review of good practice on ageing policy*, 2015.
- 7 Carman KL, Mallery C, Maurer M, *et al.* Effectiveness of public deliberation methods for gathering input on issues in healthcare: results from a randomized trial. *Soc Sci Med* 2015;133:11–20.



- 8 Molster C, Potts A, McNamara B, *et al.* Informing public health policy through deliberative public engagement: perceived impact on participants and citizen-government relations. *Genet Test Mol Biomarkers* 2013;17:713–8.
- 9 Abelson J, Montesanti S, Li K. *Effective strategies for interactive public engagement in the development of healthcare policies and program*, 2010.
- 10 Bombard Y, Baker GR, Orlando E, *et al.* Engaging patients to improve quality of care: a systematic review. *Implement Sci* 2018;13:98.
- 11 Conklin A, Morris Z, Nolte E. RAND Foundation EUROPE. In: *Involving the public in healthcare policy: an update of the research evidence and proposed evaluation framework*. 65, 2010.
- 12 de Freitas C, Martin G. Inclusive public participation in health: policy, practice and theoretical contributions to promote the involvement of marginalised groups in healthcare. *Soc Sci Med* 2015;135:31–9.
- 13 Petriwskyj A, Warburton J, Everingham J-A, *et al.* Diversity and inclusion in local governance: An Australian study of seniors' participation. *J Aging Stud* 2012;26:182–91.
- 14 Irvin RA, Stansbury J. Citizen participation in decision making: is it worth the effort? *Public Adm Rev* 2004;64:55–65.
- 15 Gauvin F-P, Abelson J, Giacomini M, *et al.* "It all depends": conceptualizing public involvement in the context of health technology assessment agencies. *Soc Sci Med* 2010;70:1518–26.
- 16 Abelson J, Gauvin F-P. Assessing the Impacts of Public Participation : Concepts. *Evidence and Policy Implications* 2006.
- 17 Gastil J, Richards R. Making direct democracy Deliberative through random assemblies. *Polit Soc* 2013;41:253–81.
- 18 OECD. *Citizens' evaluation of public participation*, 2005.
- 19 Baum HS, Neil JS, Paul BB. *Citizen participation International Encyclopedia of the Social & Behavioral Sciences*. Pergamon: Oxford, 2001: 1840–6.
- 20 Carman KL, Heeringa JW, Heil SKR. Public deliberation to elicit input on health topics. *Findings From a Literature Review* 2013.
- 21 McNeil H, Elliott J, Huson K, *et al.* Engaging older adults in healthcare research and planning: a realist synthesis. *Res Involv Engagem* 2016;2:10.
- 22 Stolee P, Elliott J, McNeil H, *et al.* Choosing healthcare options by involving Canada's elderly: a protocol for the choice realist synthesis project on engaging older persons in healthcare decision-making. *BMJ Open* 2015;5:e008190.
- 23 Keogh F, Carney P, O'Shea E. Innovative methods for involving people with dementia and carers in the policymaking process. *Health Expect* 2021;24:800–9.
- 24 Peters MDJ, Marnie C, Tricco AC, *et al.* Updated methodological guidance for the conduct of scoping reviews. *JBI Evid Implement* 2021;19:3–10.
- 25 Qays H, Uriz QH, Mahmood Z, *et al.* *Strategic framework for mainstreaming citizen engagement in world bank group operations: engaging with citizens for improved results (English)*. Washington DC: World Bank Group, 2015. <http://documents.worldbank.org/curated/en/266371468124780089/Strategic-framework-for-mainstreaming-citizen-engagement-in-World-Bank-Group-operations-engaging-with-citizens-for-improved-results>
- 26 Alliance FC. *Caregiver Statistics: Work and Caregiving Definitions Juggling Work and Caregiving Impact on Working Caregivers*. 2016.
- 27 Canadian Institutes of Health Research. *CIHR's Framework for Citizen Engagement: Partnerships and Citizen Engagement Branch*. Ottawa, Ontario K1A 0W9 Canada: Canadian Institutes of Health Research; 2012. <https://cihr-irsc.gc.ca/e/41270.html><https://cihr-irsc.gc.ca/e/41270.html>
- 28 Carman KL, Dardess P, Maurer M, *et al.* Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff* 2013;32:223–31.
- 29 Arnstein SR. A ladder of citizen participation. *J Am Inst Plann* 1969;35:216–24.